



**NJ Department of Health
Governor's Council for Medical Research and Treatment of Autism
Council Meeting Minutes (ratified)
September 18, 2017**

Council Members Present

Michael Aquino, MD, F.A.C.G., Senate President Appointee; Partner, Shore Gastroenterology Associates; Co-founder, VP of Operations, Pathology Solutions

Cheryl F. Dreyfus, Ph.D., Academic Institution Representative; Professor and Chair, Department of Neuroscience and Cell Biology, Rutgers University, Robert Wood Johnson Medical School

***Caroline Eggerding, MD**, Healthcare Organization Representative; Division Head, Department of Pediatric Neurology and Development, Cooper Children's Regional Hospital

Susan P. Evans, Ed.D., Commissioner of Health Appointee; Education Program Specialist for Early Intervention Program, NJ Department of Health

Wilma Judith Friedman, Ph.D., Academic Institution Representative; Professor, Department of Biological Sciences, Rutgers University

Thomas V. Macchiaverna, MA, Public Member Representative; Special Education Teacher

Samuel Sheng-Hung Wang, Ph.D., Academic Institution Representative; Professor, Department of Molecular Biology and Princeton Neuroscience Institute, Princeton University

*Denotes Council Chairperson

Absent

B. Madeleine Goldfarb, MA, Autism Organization Representative; Founder/Director of the Noah's Ark Institute

Ketan Kansagra, MD, FAAP, Academic Institution Representative; Neonatologist, Division of Neonatal Medicine, Children's Hospital of New Jersey at Newark Beth Israel Medical Center

Michele Sorvino, RDMS, Speaker of the General Assembly Appointee; Executive Director,

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Golden Door International Film Festival of Jersey City

Gary Weitzen, BA, Autism Organization Representative; Executive Director of POAC (Parents of Autistic Children)

NJ Department of Health (DOH) Attendees

Martin T. Zanna MD, MPH, Acting Executive Director
Governor's Council for Medical Research and Treatment of Autism

Linda N. Bocclair, M.Ed., MBA, Executive Assistant
Governor's Council for Medical Research and Treatment of Autism

Mary Ray, Contract Administrator 2
Governor's Council for Medical Research and Treatment of Autism
Commission on Brain Injury Research and Commission on Spinal Cord Research

Daphne Robinson, Ph.D., Consultant
Scientific Planning Consulting

Public Attendees

Karen Hood-Kasim MPH, Project Coordinator, NJ ACE Coordinating Center

Cecelia Feeley, Ph.D., Rutgers University

Richard Dreyfus

Note: Motions are numbered.

I. Welcome - Council Chairperson, Dr. Caroline Eggerding called the meeting to order at 6:10 PM and welcomed everyone.

II. Public Meetings Act Announcement - Dr. Eggerding read the Public Meetings Act.

III. Approval of the June 5, 2017 Council Meeting Minutes-Dr. Eggerding called for a motion to approve the minutes. MOTION by Mr. Macchiaverna to approve the minutes was seconded by Dr. Aquino.

1. MOTION to approve the minutes was passed with two members in favor and four abstentions. One member arrived later (did not vote).

IV. Approval of the 2018 Council Meeting Calendar- Dr. Eggerding called for a motion to approve the calendar. MOTION by Dr. Dreyfus to approve the calendar was seconded by Dr. Friedman.

2. MOTION to approve the calendar was passed with all members in favor. One member arrived later (did not vote).

V. Conditional Continuation Funding for CAUT16MED002-- Dr. Eggerding called for a motion to approve with conditions continuation funding for CAUT16MED002. MOTION by Mr. Macchiaverna to approve with conditions continuation funding for CAUT16MED002 was seconded by Dr. Dreyfus.

Discussion. The grantee, the Institute for Child Development (ICD) at Hackensack University Medical Center (HUMC), has made considerable progress in addressing each of the deliverables required by the grant. However, the ICD has fallen short in ensuring comprehensive, coordinated care for ICD patients by engaging in active partnership with primary care physicians. Five physicians, each representing either a solo or a group primary care practice wrote letters of support for the ICD Hackensack grant with specific expectations of the partnership with the ICD.

3. MOTION to approve continuation funding for year 2 for CAUT16MED002 with the condition the grantee will accomplish, at a minimum, the following prior to Council's January 29, 2018 meeting was passed with all members in favor. One member arrived later (did not vote).
 - Identify a liaison at each of the primary care practices (PCPs).
 - Provide letters of agreement signed by the PCP Senior Partners and Dr. Randye Huron (Principal Investigator) stating the responsibilities of each.
 - Develop and implement processes with Tenaflly Pediatrics and Advanced Pediatrics, and pediatric sub-specialists to ensure coordination of care.
 - Identify ICD patients referred from Tenaflly Pediatrics and Advanced Pediatrics by tagging those patients on ICD's master list.
 - Track ICD patients referred from Tenaflly Pediatrics and Advanced Pediatrics through the workflow map using the map to develop and implement the Action Plan addressing each component of the action plan as defined in the Request for Applications (RFA).

VI. Determination of grants to be offered in SFY19 RFA

Key discussion Points:

- \$1.5M is available for funding in SFY19.

- Medical Homes will not be included in the SFY19 RFA given the need to evaluate the outcomes of the current six grants and determine how to best capitalize on and develop the information to recommend to the Department of Health (DOH) best practices for the implementation of medical homes for autism in the state. The DOH agreed to hire a medical homes consultant to work with the Council on this issue.
- After a lengthy discussion to determine grants to be offered in SFY19 the conclusion was to offer three or four two-year post-doc fellowships at \$130,000 total each and two-year clinical research pilot projects at \$400,000 total each.

Note: During the discussion of SFY19 funding considerable time was spent questioning and then defining meaningful outcomes of current and completed Council funded research. Dr. Aquino offered to help evaluate the five research projects that have been completed since 2012. Dr. Eggerding led a discussion of meaningful outcome measures (some broad and ambitious) with the following identified:

- Additional funding to grantees from other sources to extend Council funding
- Change in public policy resulting from the research
- Publications with citations (3 years after publications)
- Researchers who become autism researchers as a result of assisting with Council funded research.
- Changes in clinical practices
- Changes in legislation
- Increased public awareness

VII. Revision of the Council's Rules of Order

Revisions to the Rules of Order will be discussed at the January 29, 2018 Council meeting. In the meantime, Council staff will identify Rules that may need to be revised and send the Rules to Council prior to the meeting. The Rules of Order were last revised on August 2, 2010.

VIII. NJACE Coordinating Center Update

Dr. Costa (1) presented a summary of the Coordinating Center's activities and services noting the Coordinating Center staff is currently overseeing a total of 34 grants and anticipates adding the two Hackensack University Medical Homes grants in the near future; (2) described plans for Part II of the Autism Summit scheduled for October 6, 2017; (3) informed Council a grant recently awarded to Rutgers U. (Barbie Zimmerman-Bier, MD) will be deferred one year due to time required to determine leadership roles and staff responsibilities due to the reorganization of the Rutgers division responsible for the grant and (4) noted his staff continues writing policies and procedures for the transfer of the NJACE to the new grantee in the event the grant is not awarded to Montclair State University.

IX. Acting Executive Director Report- Martin T. Zanna, MD, MPH

Dr. Zanna thanked Dr. Costa for his report.

Council Membership. Council staff will work with Victoria Brogan (Deputy Chief of Staff) to fill the seats vacated by Elizabeth (Liz) Bell (public member individual or public member with autism), Dana Spett (autism organization representative) and one additional autism organization representative. If members know of anyone who may be interested in serving please ask them to contact Linda Bocclair for information. Members should have received Michele Sorvino's (new member) biographical sketch. She had a previous commitment and was not able to attend tonight's meeting.

Ethics Requirements

On July 10, 2017 Linda sent an email to notify members of the annual Ethics Training requirement for Special State Officers (SSO). Two members have completed the requirement for 2017. Linda will resend the email. Members have until December 31, 2017 to complete the on-line ethics training module.

SFY'18 RFA

Three applications were received for the NJACE grant. The applications will be critiqued by a review panel with a second level of review by the Council's Scientific Advisory Committee. Council will then have access to review the critiques and the applications with voting to approve one application for the NJACE grant at their January 29, 2018 meeting.

X. Report of Revenues and Expenditures

The report was included in members' Council packets, for information.

XI. Public Comments

No public comments.

XII. Adjournment

Dr. Eggerding called for a motion to adjourn.

4. MOTION to adjourn by Dr. Friedman and seconded by Dr. Dreyfus was approved with all members in favor.

The meeting was adjourned at 9:00 PM.